

# Epidemiology

In the previous (seventh) edition of its Standards of Care, WPATH identified only a small number of articles attempting to estimate the size of the transgender and gender diverse (TGD) population and characterized the state-of-the-science as “a starting point” requiring further systematic study (Coleman et al. 2012). Since then, the literature on this topic has expanded considerably as evidenced by a number of recent reviews that have sought to synthesize the available evidence (Arcelus et al. 2015; Collin et al. 2016; Goodman et al. 2019; Meier and Labuski 2013; Zhang et al. 2020).

In reviewing epidemiologic data pertaining to the TGD population, it may be best to avoid the terms “incidence” and “prevalence”. Avoiding these and similar terms may preclude inappropriate pathologizing of TGD people (Adams et al. 2017; Bouman et al. 2017). Moreover, the term “incidence” may not be applicable in this situation because it assumes that TGD status has an easily identifiable time of onset, a prerequisite for calculating incidence estimates (Celentano and Szklo 2019). For all the above reasons, we recommend using the terms “number” and “proportion” to signify the absolute and the relative size of the TGD population.

Perhaps the most important consideration in reviewing this literature is the variable definition applied to the TGD population (Collin et al. 2016; Meier and Labuski 2013). In clinic-based studies, the data on TGD people are typically limited to individuals who received transgender-related diagnoses or counseling or those who requested or underwent gender affirming therapy, whereas survey-based research typically relies on a broader, more inclusive definition based on self-reported gender identities.

Another methodological consideration in assessing the size and distribution of the TGD population is the need to understand what constitutes the sampling frame. As noted in recent reviews (Goodman et al. 2019; Zhang et al. 2020), many of the published studies, especially those conducted more than a decade ago, first assessed the number of patients seen at a particular clinical center and then divided that number by an approximated population size. This was unlikely to produce an accurate estimate because the numerator in the calculations is not necessarily included in the denominator, and the true size of the denominator often remains unknown. With these considerations in mind, it is advisable to focus specifically on recent (published within the last decade) peer-reviewed studies that utilized sound methodology in identifying TGD people within a well-defined sampling frame. These types of studies can provide more accurate contemporary estimates.

The available studies can be assigned into three groups: 1) those that reported proportions of TGD people among individuals enrolled in large health care systems; 2) those that presented results from population surveys of predominantly adult participants; and 3) those that were based on surveys of youth conducted in schools. Of these three categories, the most informative and methodologically sound studies are summarized below. Additional details about these and other similar studies can be found in recent literature reviews (Goodman et al. 2019; Zhang et al. 2020).

Among studies that estimated the size of the TGD population enrolled in large health care systems, all were conducted in the United States, and all relied on information obtained from electronic health records. Four of those health system-based studies relied exclusively on diagnostic codes to ascertain the TGD population; two studies (Blosnich et al. 2013; Kauth et al.

2014) used data from the Veterans Health Affairs system, which provides care to over 9 million people, and two studies (Dragon et al. 2017; Ewald et al. 2019) used claims data from Medicare, the federal health insurance program that primarily covers people 65 years of age or older. The proportions of TGD people reported in these diagnostic code-based studies ranged from approximately 0.02% to 0.03%. The fifth health systems-based study (Quinn et al. 2017) was conducted at Kaiser Permanente plans in the states of Georgia and California; these plans provide care to approximately 8 million members enrolled through employers, government programs, or individually. The TGD population in the Kaiser Permanente study was ascertained across all age groups using both diagnostic codes and free-text clinical notes. The proportions of TGD people identified at Kaiser Permanente were higher than the corresponding proportions reported in the Veterans Health Affairs and Medicare studies with the most recent estimates ranging from 0.04 to 08%.

In contrast to results from the health system-based studies, findings from surveys that relied on self-reported TGD status produced much higher estimates. Two US studies took advantage of the Behavioral Risk Factor Surveillance Study (BRFSS), which is an annual telephone survey conducted in all 50 states and US territories (Conron et al. 2012; Crissman et al. 2017). The first study used data from the 2007-2009 BRFSS cycles in the state of Massachusetts, and the second study used the 2014 BRFSS data from 19 states and the territory of Guam. Both studies reported that approximately 0.5% of adult participants (at least 18 years of age) responded “Yes” to the question “*Do you consider yourself to be transgender?*”

An internet-based survey administered to a sample of the Dutch population 15-70 years of age (Kuyper and Wijzen 2014) asked participants to score the following two questions using a 5-point Likert scale: “*Could you indicate to which degree you psychologically experience yourself as a man?*” and “*Could you indicate to which degree you psychologically experience yourself as a woman?*” The respondents were considered “gender ambivalent” if they gave the same score to both statements and “gender incongruent” when they reported a lower score for their sex assigned at birth than for their gender identity. The proportions of participants reporting incongruent and ambivalent gender identity were 1.1% and 4.6%, respectively, for persons who were assigned male at birth (AMAB), and 0.8% and 3.2%, respectively, for assigned female at birth (AFAB) persons.

A similarly designed study estimated the proportion of TGD residents in the Flanders region of Belgium using a sample drawn from the country’s National Register (Van Caenegem et al. 2015). Participants were asked to score the following statements: “*I feel like a woman*” and “*I feel like a man*” on a 5-point Likert scale. Using the same definitions applied in the Dutch study (Kuyper and Wijzen, 2014), the proportion of gender incongruent individuals was 0.7% for AMAB people and 0.6% for AFAB people. The corresponding estimates for gender ambivalence among AMAB and AFAB people were 2.2% and 1.9%, respectively.

A more recent population-based study evaluated the proportion of TGD people among approximately 50,000 adult residents of Stockholm County, Sweden (Ahs et al. 2018). The numerator was determined by asking participants the following question: “*I would like hormones or surgery to be more like someone of a different sex.*” Two additional items were designed to identify individuals experiencing gender incongruence: “*I feel like someone of a different sex*” and “*I would like to live as or be treated as someone of a different sex.*” The desire for either hormone therapy or gender affirming surgery was reported by 0.5% of participants. Individuals who expressed feeling like someone of a different sex and those who wanted to live as or be treated as a person of another sex constituted 2.3% and 2.8% of the total sample, respectively.

Population-based data outside of North America and Western Europe are less common. One recent study offers valuable data from a large representative survey of 6,000 adults in Brazil (Spizzirri et al. 2021). Gender identity of participants was assessed based on the following three questions: 1) *“Which of the following options best describes how you currently feel?”* (Options: I feel I am a man, I feel I am a woman, and I feel I am neither a man nor a woman); 2) *“What is the sex on your birth certificate?”* (Options: male, female, and undetermined); and 3) *“Which of these situations do you most closely relate to?”* (Options: I was born male but I have felt female since childhood; I was born female but I have felt male since childhood; I was born male, and I feel comfortable with my body; I was born female, and I feel comfortable with my body). Based on the responses to these three questions, the authors determined that 1.9% of the survey respondents were TGD (0.7% defined as transgender, and 1.2% defined as non-binary).

The literature on the population proportions of TGD youth (persons under 19 years of age) includes several survey studies conducted in schools. A 2012 national cross-sectional survey in New Zealand collected information on TGD identity among high school students (Clark et al. 2014). Among over 8,000 survey participants, 1.2% self-identified as TGD and 2.5% reported they were not sure. Another study of schoolchildren was based on a 2016 survey of 9<sup>th</sup> and 11<sup>th</sup> grade students (ages 14-18 years) in Minnesota, United States (Eisenberg et al. 2017). Of the nearly 81,000 survey respondents, 2.7% reported being TGD. A more recent study (Johns et al. 2019) presented results of the Youth Risk Behavior Survey (YRBS), which is conducted biennially among local, state, and nationally representative samples of US high school students in grades 9-12 (approximate age range 13-19 years). The 2017 YRBS cycle was carried out in 10 states and 9 large urban areas and included the following sequence: *“Some people describe themselves as transgender when their sex at birth does not match the way they think or feel about their gender. Are you transgender?”* Among nearly 120,000 participants across the 19 sites, 1.8% responded *“Yes, I am transgender,”* and 1.6% responded *“I am not sure if I am transgender.”*

Another recently published school-based study in the United States presented results of a 2015 survey conducted in Florida and California with the aim of identifying gender diverse children and adolescents in a sample of just over 6,000 students in grades 9-12 (Lowry et al., 2018). *“High gender-nonconforming”* was used to define AMAB children who reported being very/mostly/somewhat feminine or AFAB children who reported being very/mostly/somewhat masculine. Based on these definitions, the proportions of TGD participants were reported to be 13% among AMAB students, 4% among AFAB students, and 8.4% overall.

Only one study examined the proportion of self-identified TGD children in a younger age group. Shields et al. analyzed the data from a 2011 survey of 2,700 students in grades 6-8 (age range 11-13 years) across 22 San Francisco public middle schools (Shields et al. 2013). Thirty-three children self-identified as TGD based on the question *“What is your gender?”* where the possible responses were *“female, male, or transgender.”* The resulting proportion of transgender survey respondents was 1.3%. However, this definition would exclude TGD persons self-identifying as non-binary and those who do not explicitly identify as transgender.

Taken together these data indicate that among health system-based studies that relied on diagnostic codes or other evidence documented in the medical records (Blosnich et al. 2013; Dragon et al. 2017; Ewald et al. 2019; Kauth et al. 2014; Quinn et al. 2017), the proportions of TGD people reported in recent years (2011-2016) ranged from 0.02% to 0.08%. By contrast, when the TGD status was ascertained based on self-report, the corresponding proportions were orders of magnitude higher and reasonably consistent, if the studies used similar definitions. When the surveys specifically inquired about *“transgender”* identity, the estimates ranged from

0.3% to 0.5% among adults and from 1.2% to 2.7% in children and adolescents. When the definition was expanded to include broader manifestations of gender diversity, such as gender incongruence or gender ambivalence, the corresponding proportions were higher: 0.5% to 4.5% among adults and 2.5% to 8.4% among children and adolescents.

As reviewed elsewhere (Goodman et al. 2019), another noteworthy observation is the continuous increase in both the size and the composition of the TGD population with upward trends in the proportion of TGD people observed in health care systems, through population-based surveys, as well as in the data on legal gender recognition. The temporal trends in AMAB to AFAB ratio have also been reported in studies analyzing referrals to clinics as well as data from integrated health systems; this ratio has changed from predominantly AMAB in previous decades to predominantly AFAB in recent years, especially among TGD youth (Aitken et al. 2015; de Graaf et al. 2018a; de Graaf et al. 2018b; Steensma et al. 2018; Zhang et al. 2021). The trend towards a greater proportion of TGD people in younger age groups and the age-related differences in the AMAB to AFAB ratio likely represents the “cohort effect,” which reflects sociopolitical advances, increased access to health care and to medical information, less pronounced cultural stigma, and other changes that have a differential impact across generations (Zhang et al. 2020).

In summary, the available data clearly indicate that TGD people represent a sizable and growing proportion of the general population. Based on the credible evidence available to date, this proportion may range from a fraction of a percent to several percentage points depending on the inclusion criteria, age group, and geographic location. Accurate estimates of the proportion, distribution, and composition of the TGD population as well as a projection of resources required to adequately support the health needs of TGD people should rely on systematically collected high-quality data, which are now increasingly available. The variability in the definitions of what constitutes the TGD population and the differences in data collection methods can be reduced by improving international collaborations.

**Summary of reported proportions of TGD people in the general population**

Health systems-based studies: 0.02-0.1%

Survey-based studies of adults: 0.3-0.5% (transgender), 0.5-4.5% (all TGD)

Survey-based studies of children and adolescents: 1.2-2.7% (transgender), 2.5-8.4% (all TGD)

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